Supporting an elderly homeless population:
Palliative care and Frailty
Erasmus project April 2023

Dr Caroline Shulman

Clinician and researcher in inclusion health

Honorary Senior Lecturer UCL, Pathway Clinical Research Fellow

Caroline.Shulman1@nhs.net @carolineshulman

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Dying as a homeless person

Deaths are often sudden, untimely and undignified, with access to palliative care being very unusual
(Crisis report 2012)

Nick (52)

Gemma (28)

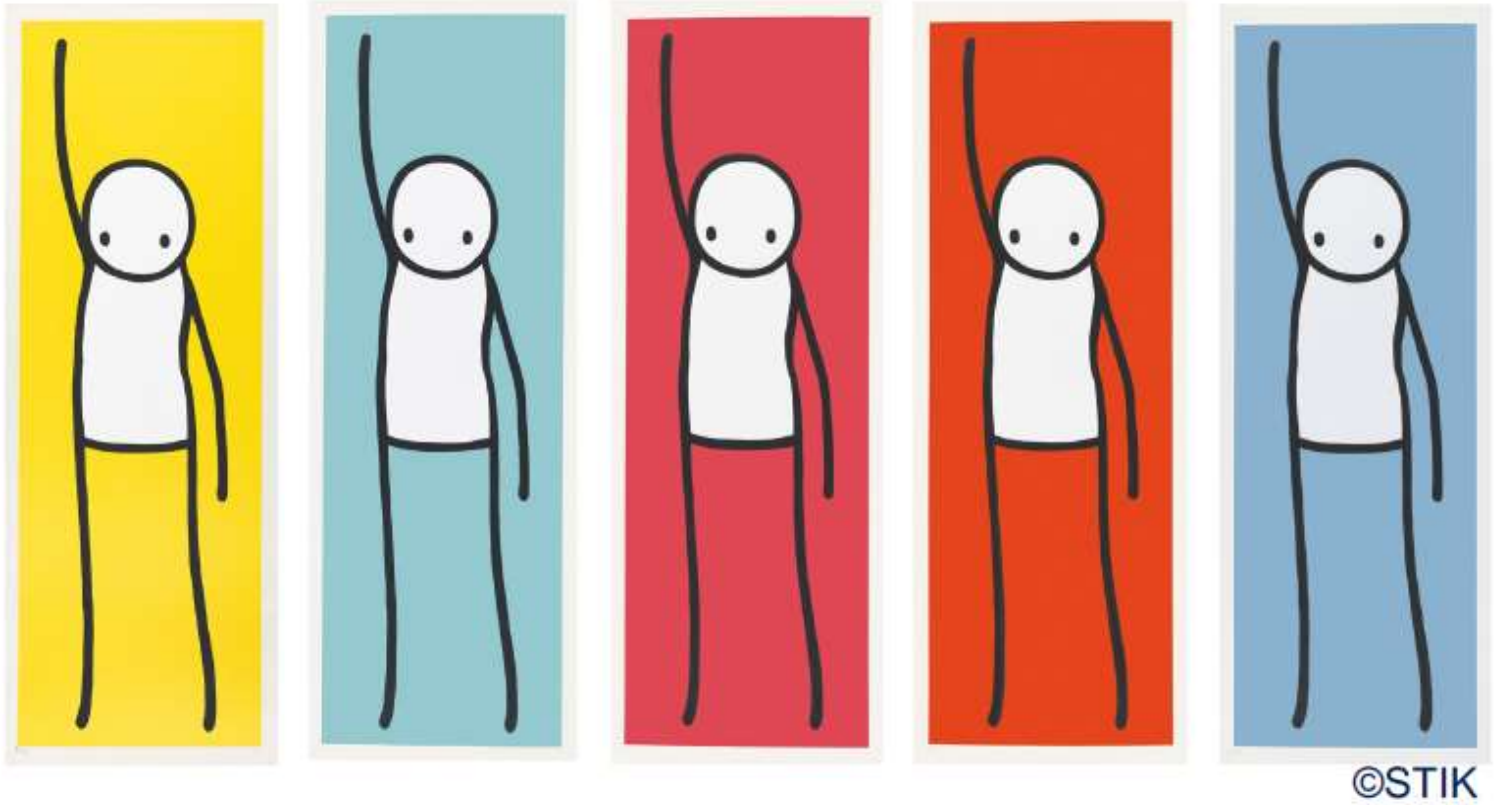
How can we improve palliative care for people who are homeless?

What is Palliative Care?

Palliative care

- is a holistic multidisciplinary approach in the care and support of people with a life limiting condition and advanced ill health
- aims to help people have a good quality of life
- can occur alongside active treatment

What we know from research



Shulman C, Hudson B F, Low J, Hewett N et al (2018). Palliative Medicine 32(1): 36-45 https://doi.org/10.1177/0269216317717101
Hudson BF, Shulman C, Low J, et al (2017). BMJ Open 2017;7:e017502. doi:10.1136/ bmjopen-2017-017502
Shulman C, Nadicksbernd, Nguyen T, et al People living in homeless hostels health and care needs (in press)

Why people are not accessing palliative care:
Lack of identification: Young age

"I think that people are just resistant to the concept of them [people who are homeless] being palliative patients. You are dealing with people who are still relatively young...it's difficult".

Specialist GP

Why people are not accessing palliative care:

Lack of identification: Uncertainty and complexity

Disease trajectory

Substance misuse & complex behaviour

Lack of access to and utilisation of mainstream services

Many deaths are sudden, but not unexpected

They sort of…could be classed as palliative but they are also reversibly palliative. So if you don't stop drinking, if you don't stop doing these things, then you are probably going to die in 6 months. And it's a little bit difficult sometimes to class them as palliative, when you have a reversible cause to it. **Healthcare professional**

The often young age and uncertainty results in people not being considered for referral to palliative care

Gaps in current systems

lack of options in place of care

Many people with very complex needs, at risk of dying, are in hostels or temporary accommodation

Gaps in current systems:

People with complex needs often remain in hostels and lack support

...we're trained to do recovery.... our hostel is commissioned to engage people with support and recovery... getting better, moving into jobs, whatever..

"At least three times a shift we check she's okay. It's hard... particularly on weekends and nights when we only have two staff... it's a big hostel [60 residents]... this isn't an appropriate environment, but it's the best we have" **Hostel staff**

- Homelessness services role is to support people into recovery
- Hostels are designed to provide temporary accommodation
- Staff left to support people with increasing complexity
- Staff go way over and above their role
- Often struggle to get adequate medical support or support from social services
- High rates of staff burnout

Gaps in Current systems:
Lack of options for place of care

Most care homes are for people with dementia who are older; it's just, it's our patients just don't fit any of these like rigid things....the care homes themselves are like 'what?! 'We don't want this 29 year old"...? **Specialist nurse**

Gaps in Current systems

- Lack of alternative places of care due to:
  - Young age
  - Mental health difficulties
  - Substance misuse

Findings: Lack of Advance Care Planning

Lack of confidence

Denial - from all sides

Concern about fragility & removing hope

Uncertainty of prognosis

Lack of options to offer

What's can help / what's needed?

- Being trauma informed
- Recognise what is happening: Better identification of those that might benefit from palliative care or need other health and care input
- Multidisciplinary support (including adult social care) taken to where people are
- Shared understanding and training for all professional groups

Being trauma informed

- Compassionate response, recognition and understanding that some behaviour or mental distress is a result of past trauma
- Recognition that for healing, there is a need for continuity and time to develop trust
- Recognise risk of re-traumatisation if not understood
- Shifts focus
  - Help people recognise that their substance use is their coping mechanism to deal with what has happened to them,
  - ie shift from *"there is something wrong with me"* to *"I am suffering and reacting to what happened to me"*
- Recognition that staff can experience vicarious trauma

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How understanding impact of trauma can help

- When with a client, it's helpful to consider 'how is trauma operating here?'
- Consider the impact trauma may be having on behaviour – anger is often a result of fear and distress
- Acknowledgement that they are attempting to deal with something awful or shameful is a huge relief: giving a sense of not being judged, having their experiences validated can be transformational

You're already doing this by letting someone tell their story and validating their experience and acknowledging how they feel, and that the behaviour is a way of coping

Listening, bearing witness and developing a trusting relationship has huge potential for helping people turn their lives around.

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Better identification and earlier recognition of people who might benefit from palliative care support: how to work with uncertainty

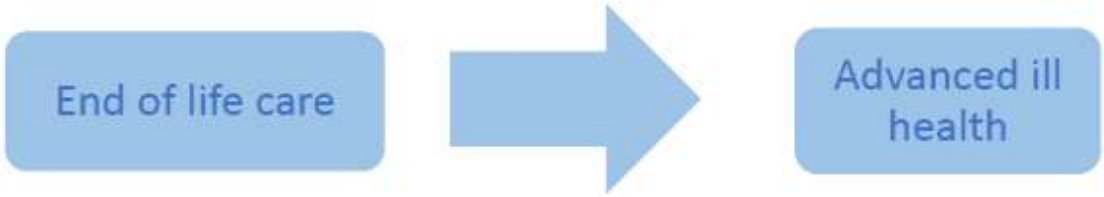
A Shift in Approach:

Supporting engagement and conversations, keeping options open

- Person-centred exploration of insights into illness, wishes and choices around living well
- Not centred around giving warnings
- Early & repeated conversations
- Shared understanding of palliative care and what it can offer: not giving up on someone, active treatment can continue
- Recognise that not everyone can recover, we cannot 'fix' people
- *Where possible respect and explore choices even if we feel they are unwise*

Taking support to where people are

A Shift in Focus:



***Choice* in *Place* of Care and *Care* in *Place* of Choice**

- **Multiagency support taken to where people are, eg hostels / own home:**
  - In-reach into hostels by health and social care professionals with regular meetings to discuss clients of concern, and provide support to both staff and residents
  - Help support decision making in complex situations: safeguarding / autonomy
    - Help advocate for appropriate care and support eg around care act assessments
    - Support staff with training
- **Collectively advocate for more alternative places of care such as high support need facilities**
- **Training for all professional groups**

Training and Support:

Developing a shared understanding

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Homeless palliative care toolkit

- Identifying Clients
- Assessing Needs
- Sharing Care
- Communication
- Bereavement
- Practicalities after a death
- Self Care

www.homelesspalliativecare.com

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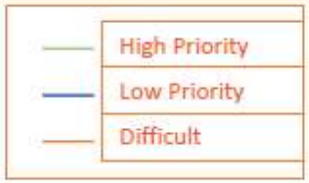
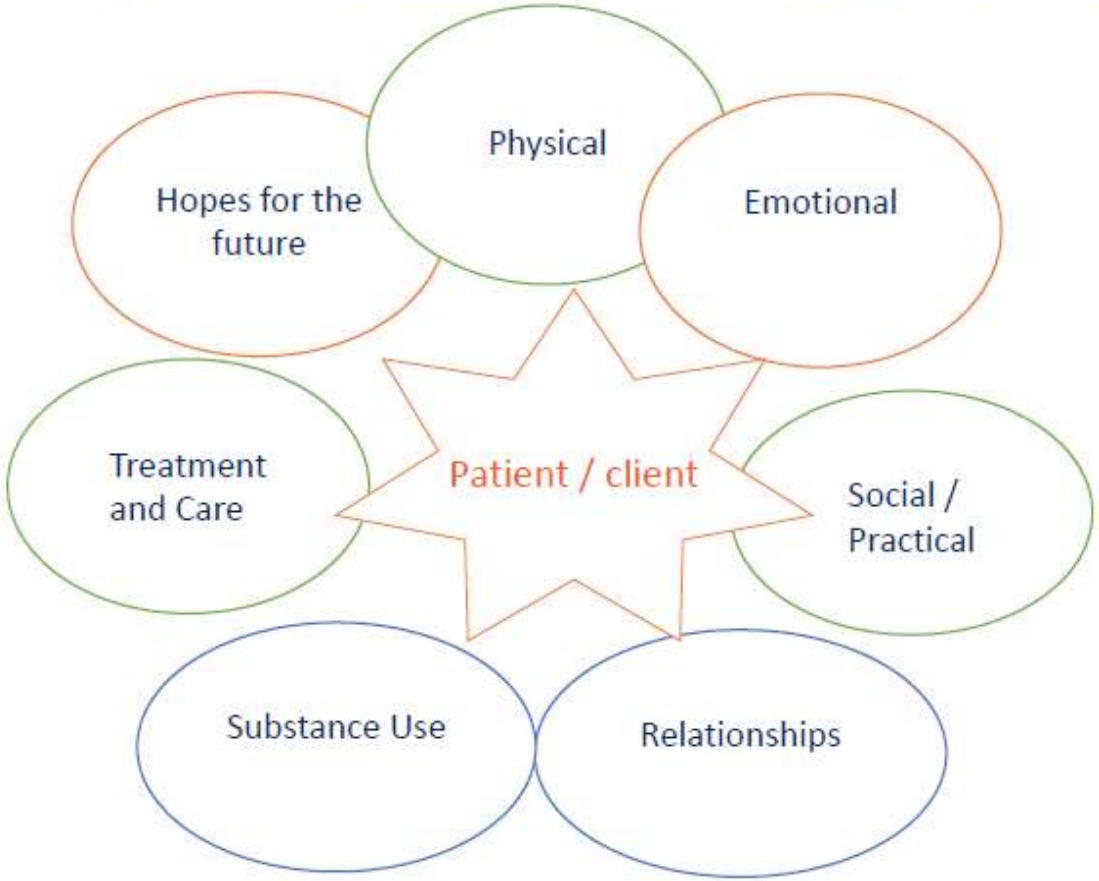
Person centred care - support and concerns mapping

start from where client is and work alongside them

- Place patient in centre
- Locate important issues to address
- Colour lines according to priority





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Questions to consider

PHYSICAL

- Do you have thoughts about where things are going with your illness?
- What do you understand about your current health situation?
- What are your main concerns?
- What would you like to see happen next?

SUBSTANCE USE

- Do you wish to reduce your drinking/substance use?
- Say you struggled to stop drinking, what do you think might happen in the next 3/6/9 months?
- Would you like to go to detox/rehab?
- Can we make a plan to meet again in a few days/weeks/months, and see where you're at with everything then?

TREATMENT AND CARE

- Do you feel you need any extra support with your care (nursing or personal care)?
- Are you having any difficulties getting around?
- If you became very ill, where would you want to be cared for? Here at the hostel, in a hospital or a hospice?
- Would you like to talk to your GP/doctor about what treatments you want/do not want?

EMOTIONAL

- How are you feeling about your recent diagnosis/hospital admission/poor health?
- I've noticed you seem a bit withdrawn lately, can I help with anything?
- Would you like to tell me about your concerns/worries?
- What do you feel would help right now?

HOPES FOR FUTURE

- What is most important to you at the moment?
- Are there things you have always wanted to do?
- Would you like support to reconnect with family?

SOCIAL / PRACTICAL ISSUES

- Have you been having trouble attending appointments, could we help with this?
- Have you thought about making a will or letter of wishes?
- What do you want to see happen with your possessions/pets after you die?
- Have you ever thought about how you'd like to be remembered?

RELATIONSHIPS

- Who are the people you trust the most?
- Who would you like to be there if you got ill (again)?
- Who would you NOT want to be there if you got ill?
- Would you like to get in touch with family?

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Activity worksheet:

Identifying clients of concern

- Are there current clients you are concerned about (e.g. a notable deterioration in health), or an **no** to the surprise question (*'Would I be surprised if they were to die in the next 6 to 12 months'*) ?
- Use this activity sheet to help you **gather your thoughts** when you have identified clients of concern, using a separate one for each client. Once completed, consider any **actions** you can take.
- Actions can take the form of people you need to talk to, (including the client), practical tasks, (e.g. proposing a multi-agency meeting), fact-finding (e.g. gathering more medical information).
- Consider whether each action is 1-to-1, a team action, or one jointly shared with members of the multi-agency team.
- This sheet can be completed at different times to reflect changing needs, (e.g. a further deterioration in their health), and to help explore concerns with clients and other professionals.
- How might the SPICT4-All tool, liver map, and shared care section of the main toolkit help you? Who else can help you to explore clients' concerns with them?

What are your concerns? *e.g. presenting physical signs and symptoms, notable changes in physical/ mental health, more admissions to hospital, place of care issues at the project.* Remember, many concerns may not have a known medical diagnosis/prognosis, and this is ok. You are simply recording your concerns, many of which may be a gut feeling.	**Thoughts and actions**
What is their current health status? *e.g. known medical diagnosis/prognosis, presenting physical signs and symptoms. Do you need more medical information?*	**Thoughts and actions**
What does the client think? *e.g. about their poor health?, how well they are managing?, if not managing, how open are they to talking to you and others?, coping strategies, and any worries you may have about how they are managing.*	**Thoughts and actions**
Multi-agency response *e.g. who already is involved? Who else needs to be involved? Have recent multi-agency meetings addressed concerns, or is there enough concern for you to set up a multi-agency meeting now?*	**Thoughts and actions**

Multi-agency prompt tool

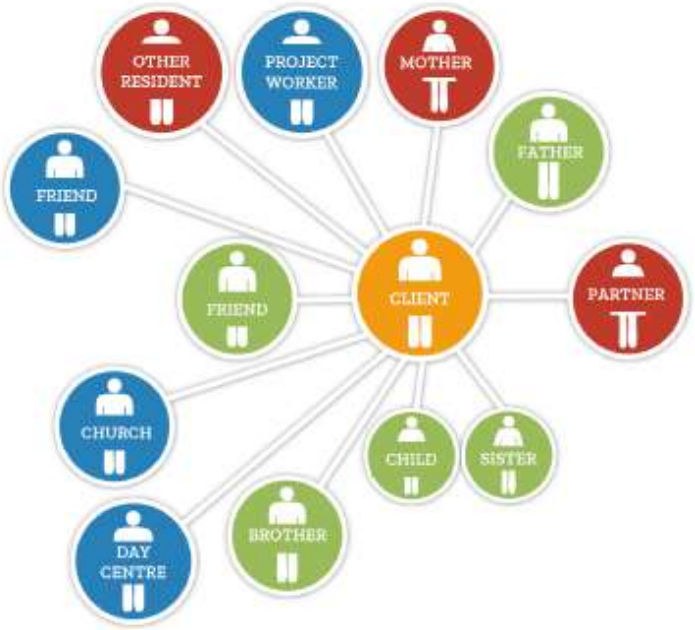
Use this tool to prepare for a multi-agency meeting and to list any actions from the meeting.
For each client whose health you are concerned about, complete a new sheet

	Client – concerns / wishes / desired outcomes (if discussed)	**Project** – concerns / needs / desired outcomes	**Actions** – outcomes from the case review
Physical health • Current health status • Notable changes (if any) • Current / Future health needs • Engagement with health services			
Mental / Emotional well-being • Current mental health issues • Psychological difficulties • Insight / Impact of illness • Ability to express feelings			
Substance Use • Current usage (if any) • Notable changes • Engagement with addiction services • Current / Future support needs			
Place of residence • Medical / nursing concerns • Personal care issues • Place of care issues • Concerns about mobility / access • Health and safety concerns • Impact on staff and other residents			
Supportive networks • Relationships / significant others *(family / friends / peers / staff / other professionals)*. See *ecomap* in the end of life care section of the toolkit • Those most/least significant and supportive • Reconnecting with family			

Eco-map tool

Benefits

- Useful when exploring with clients the people and organisations most important to them, and the kind of support, if any, they can provide
- Can support opening up conversations about what really matters to clients i.e. people they may wish to reconnect with (or not)
- Helps us to consider the needs of those people and organisations important to the client, including after the client dies
- Enables us to revisit the significance of the people and organisations in a client's life as needs change (i.e. notable changes in health, approaching end of life)



- A **strong** connection suggests a good level of emotional and practical support
- A **weak** connection suggests little or no emotional and practical support
- A **stressful** connection implies someone significant to the client who may bring additional stress or distress to them. Though a stressful connection, they remain important to the client, which needs to be acknowledged when planning physical and emotional supports